Discharging patients home from hospital at the end of life

This article provides an overview of important considerations for the non-palliative care specialist when discharging a dying person home to his or her preferred place of care. A highly practical framework is included for identifying and assessing the patient's needs, and devising a tailored care plan.

Many people, when given the choice, would prefer to spend their final days at home, surrounded by loved ones (Gomes and Higginson, 2006). Helping people to achieve this can result in an improved experience of end of life care for the person, those important to him/her, and the staff involved in the person's care (Department of Health, 2008).

To enable this, it is vital that health-care professionals are aware of the steps involved in transferring the care of someone from hospital to home, and how to best facilitate this process. At times a rapid discharge will be required, which poses its own challenges.

Rapid discharges at the end of life are complex processes which require the input of multiple health-care professionals at every stage. With appropriate assessment and a framework to work from, such discharges can be successful. The following key components for a rapid discharge are explored in greater depth in this article:

- Recognition that the person has a deteriorating condition and may be dying, and communication with the person and/or carers such that they are aware of the situation
- Finding out what the person wants, including options around preferred place of care and death
- Assessment of clinical and care needs
- Provision of an individually-tailored care plan and package of care to support the person's needs
- Effective liaison with and communication of the person's needs and wishes to appropriate community services
- Exceptional circumstances or unusual situations (emergency department, outpatients, abroad, addiction, homelessness).

Recognition and communication

Earlier identification of deterioration and the recognition of dying

Key to this whole process is that clinicians are able to recognize deterioration, and specifically the possibility that a person might be in his/her final days or weeks of life. Since the demise of the Liverpool Care Pathway, there has been a shift in focus from definite diagnosis of 'dying' to a more nuanced approach where uncertainty is acknowledged, continual reassessment is undertaken of the clinical situation and the patient's needs and wishes, and where care is responsive (Independent Review of Liverpool Care Pathway, 2013).

The pivotal document 'One Chance to Get It Right' (Leadership Alliance for the Care of Dying People, 2014), released in the aftermath of the Liverpool Care Pathway, highlights the focus on:

> **'recognition of patients who are clinically unstable and may not recover despite medical treatment, so that those patients and those important to them are as involved as much as possible in decisions being made about their care'.**

The authors also stress the importance of involving senior medical staff at this important transition when decisions need to be made.

The Royal College of Physicians (2016) found the median time between recognition and death in acute hospitals was just 34 hours, and for a quarter of cases it was less than 11 hours, leaving little time for exploring options around end of life care preferences. It is important to try and identify a deteriorating trajectory before the late stages of dying are evident, as usually the person will be too unstable to transfer at this point, and opportunities to achieve preferred place of death may be missed.

No one sign or symptom can reliably predict dying, but the features listed in *Figure 1* may occur.

Communication

Individuals and their families need to know they are approaching the end of life and need to be involved in the decision making and planning (National Palliative and End of Life Care Partnership, 2015).

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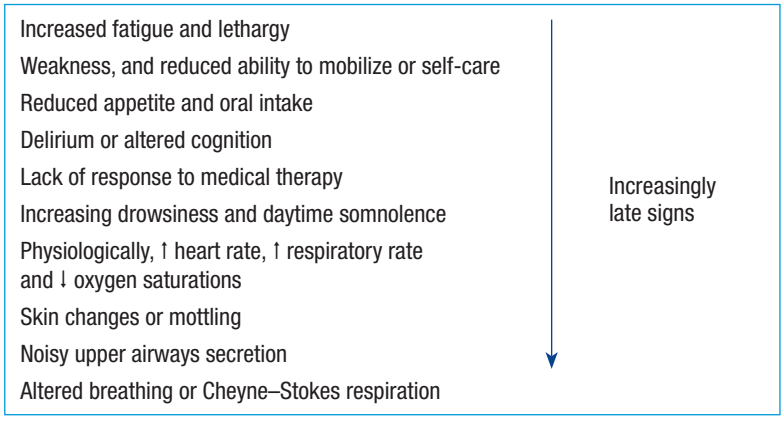
Figure 1. Features that may suggest a person is nearing end of life.



Although the responsibility for such conversations sits with a senior member of the patient's treating team all doctors will be involved in these conversations with patients and those important to them.

Key areas to focus on could include:

- The current clinical condition (deteriorating rapidly – may now be dying)
- Significant discussions about prognosis
- Significant changes to management
- Ceiling of care or appropriateness of cardiopulmonary resuscitation
- Decisions to stop or make changes to disease-modifying treatment
- Acknowledgement of uncertainty.

Effective open and honest conversations with the person and those important to him/her are essential for the coordination of a successful rapid discharge for end of life care. Wishes and preferences may change at any time throughout this process (Sue Ryder, 2013).

What does the person want? What is important to him/her?

Exploring preferred place of care and preferred place of death

When there is acknowledgement that the person may be in the last days or short weeks of life, discussion of preferences and wishes should include preferred place of care and death (noting that the two are not necessarily synonymous).

Many patients would not elect to spend their final days or weeks in hospital if given the choice, although in England around half of people will die in hospital (Public Health England, 2015).

Discussions must take into account the views of relatives and loved ones, as these people often end up undertaking some of the care burden, and may feel unsupported to manage distressing symptoms and complex care needs in the home environment. There is also evidence that people change their mind about preferred place of death the nearer they are to death (Sue Ryder, 2013) and that for many home may not always be the best place of care. If symptoms remain complex or distressing and/or dependency increases, care in the community might not always be appropriate or available to maintain adequate care provision, resulting in crisis readmissions (Department of Health, 2008).

As with any important decision making, the mental capacity of the patient must be assessed, and if the person lacks capacity in this regard, then decisions need to be made and documented clearly using the Best Interests framework (Department of Health, 2005), keeping the person at the heart of the decision-making process.

Assessing clinical and care needs and providing an individually tailored package of care

Assessment

Between the multidisciplinary team caring for the person, the following need to be assessed and addressed, ideally via a care planning meeting involving the person and family or carer and members of the multidisciplinary team both from the hospital and community.

General situation and estimation of prognosis and/or unpredictability and/or rate of deterioration

Would this person be suitable for continuing care fast track funding? Nationally this enables quick access to funding for someone with a rapidly deteriorating condition which may be entering the terminal phase. In order to aid decision making, a full clinical picture should be included on the fast track form, including details such as diagnosis, prognosis and the rationale behind the decision to commence palliative or end of life care.

How rapidly does discharge need to occur? Rapid discharge timeframes vary, but there is an aim to transfer the person to his/her preferred place of care or death with minimum delay. For those who are imminently dying time is of the essence and every effort should be made to achieve preferred place of death safely within the same or the next day. Many hospitals have developed tools to support this process such as the 'rapid discharge plan' (see below).

Assessment of physical and symptom needs

What medication is currently required to improve quality of life or symptoms (and what can be stopped to reduce medication burden)? All medication should be reviewed, and rationalized where possible. Medication should only be continued if it is likely to benefit the person in terms of symptoms or prevent major problems (e.g. antiepileptic medication). Drugs for cardiovascular prevention can usually be stopped. Careful consideration should be given to treatments that are particularly invasive or unpleasant (e.g. intravenous antibiotics, low molecular weight heparin as to their ongoing necessity). Minimize tablet burden where possible.

Who needs to continue to manage symptoms in the community? Symptom management is usually carried out by the GP alongside district nurses and/or the community specialist palliative care team. Current and future needs should be made clear on the discharge documentation.

Is the person on oxygen? Review the need for oxygen therapy. Is this still of benefit for the person? If oxygen is required, complete the appropriate home oxygen order form (HOOF). Ensure that oxygen is delivered and in situ at the discharge address before the person leaves hospital.

Assessment of care needs

Does the person have a syringe pump, catheter, pressure area care plan or other nursing need? Does the person require carers to help with activities of daily living? Is a night assessment required?

Does the person require any specialist equipment which may need to be ordered (e.g. profiling bed, mattress, commode)? Consider occupational therapy assessment at this stage (if appropriate) to assess mobility and determine future care needs. Referral to district nurses will be required for ongoing care.

Anticipation of future problems

Is the person in the last days of life and at risk of suffering from uncontrolled symptoms? If so then supplying anticipatory as-required (prn) subcutaneous medication is usually appropriate (*Figure 2*).

Is the person at risk of a specific event, e.g. catastrophic bleeding from an invasive neck tumour, or seizure from a cerebral metastasis? A specific care plan may be appropriate, and/or the provision of written or verbal information to the person or family.

What should the person or family do in the event of deterioration – is readmission to hospital appropriate in any circumstances or if needs cannot be met in the community is there an alternative such as hospice?

Assessment of information needs

Does the person and the family know what to expect in the coming days or weeks? There is a huge wealth of resources available to supplement face to face communication. Locality-specific leaflets may be available, but in the absence of these, information and leaflets on what to expect in the last days and weeks of life can be downloaded from sites such as Macmillan Cancer Support, Dying Matters and registered charities such as Compassion in Dying and Age UK.

Do they need any information to support discussions with children? Provision of specific support for children will vary depending on locality, but for general advice, the charity Winston's Wish is a useful resource for information for patients and professionals.

Do they need information in other languages or formats? Local and national documents are often available in other languages and formats; information on how to access these can be found on the back page of most publications.

Are there financial concerns? Consider discussion with the allocated joint care manager or medical social worker, or use of the Macmillan benefits line.

Figure 2. Example of anticipatory as-required (prn) medication in a patient not currently receiving regular medication.

Patients at home who develop symptoms can experience delays in obtaining symptom relief as a result of availability of community staff out-of-hours and the need for families to collect community prescriptions, thus taking them away from care. Prescribing anticipatory medication reduces such delays enabling prompt administration of the available medication by district nurses.

Anticipatory medication needs to be considered on an individual basis, taking into account the elderly or frail patient, patient preferences, as well as liver and renal function, and likelihood of developing symptoms.

Pain

Morphine sulfate 2.5 mg subcutaneous, hourly prn. Max four doses in 24 hours

Nausea and vomiting

Levomepromazine 2.5–6.25 mg, hourly prn. Max dose 12.5 mg in 24 hours

Secretions

Hyoscine butylbromide 20 mg subcutaneous, hourly prn. Max 80 mg in 24 hours

Agitation

Midazolam 2.5–5 mg subcutaneous, hourly prn. Max four doses in 24 hours

Delirium

Haloperidol 1–3 mg subcutaneous, hourly prn. Max 6 mg in 24 hours

Care planning

Care planning meetings with the multidisciplinary team provide an opportunity to discuss in full the person's current and future needs, risks involved in a rapid discharge at the end of life, care that can be provided in the community, and limitations such as availability and appropriateness of services.

It is not uncommon when details and practicalities are discussed for people to change their minds at this stage and opt for an alternative place of care (The Choice in End of Life Care Programme Board, 2015). For some, knowing that all possibilities have been explored is of comfort, even if they are not able to achieve their ideal preferred place of care or preferred place of death.

There are a number of professionals who will potentially be involved in the care planning or transfer of care at the end of life from hospital to community (*Figure 3*) and it is important that professionals share information about the clinical situation and the person's preferences.

Sharing information between organizations

The exact format of discharge correspondence may vary, but it is imperative that useful communication occurs to the usual GP practice, primary care out-of-hours providers, the district nursing team, care home staff and community specialist palliative care team or hospice where appropriate. As well as medical details, it is good practice to include the following details:

- Presence of do not attempt cardiopulmonary resuscitation form
- Under what circumstances (if any) readmission to hospital would be appropriate
- Advance decisions in terms of ceiling of treatment (e.g. antibiotics, non-invasive ventilation)

Figure 3. Key people who may be involved in a discharge at the end of life, alongside the medical team.

The ward nurse has in-depth knowledge of the patient's current care needs and can work in partnership with the district nurse to coordinate a suitable plan of care

The district nurse is often the keyworker for a dying person in the community, coordinating and delivering generalist palliative care on a daily basis. The district nurse has responsibility for ensuring care is continually reviewed to support the needs of both the person and family

A joint care manager or medical social worker will be allocated to coordinate the fast track discharge process and will source or commission any additional agency care required to support the district nurse. The joint care manager or medical social worker can also support with financial concerns or benefits and explore any fears and anxieties the patient or family may have about coping at home on discharge

An occupational therapist is crucial to the safe planning of a patient's discharge and can help determine the equipment and environmental needs (may require environmental home visit or assessment). The occupational therapist can also liaise with the ambulance service to identify any risk associated with moving and handling during transfer

Pharmacists provide guidance and advice for current and anticipatory prescribing at the end of life

The hospital specialist palliative care team provide specialist advice on the management of physical symptoms or other palliative care needs before discharge, and will also be able to support with complex discharge planning

The community specialist palliative care team support with ongoing challenging symptoms or other palliative care needs which require specialist follow up in the community

The GP will usually have medical responsibility for the patient once at home, and may have a professional relationship with the patient and the wider family extending over many years, giving the GP a unique insight into the patient's home situation

A dedicated palliative care ambulance service (if available) can provide a bespoke flexible, prompt, transport service for palliative patients reducing potential delay and anxiety for both patient and family

Figure 4. Do not attempt cardiopulmonary resuscitation (DNACPR) – legal update.

In June 2014 the Court of Appeal found that doctors had acted unlawfully when they placed a do not resuscitate order on Janet Tracey without consultation (R (Tracey) v Cambridge University Hospital NHS Foundation Trust & Ors [2014])

The latest guidance from the British Medical Association et al (2016) states:

'Even when cardiopulmonary resuscitation has no realistic prospect of success, there must be a presumption in favour of explaining the need and basis for a DNACPR decision to a patient, or to those close to a patient who lacks capacity. It is not necessary to obtain the consent of a patient or of those close to a patient to a decision not to attempt cardiopulmonary resuscitation that has no realistic prospect of success. The patient and those close to the patient do not have a right to demand treatment that is clinically inappropriate and healthcare professionals have no obligation to offer or deliver such treatment.'

- Patient preferences around preferred place of care and death
- The patient's understanding of the situation and any communication preferences (e.g. does not wish to know prognosis)
- Next of kin details where appropriate.

Discharge letter to the GP (may be electronic)

For complex patients who are rapidly deteriorating consider person to person contact (telephone call with the GP) alongside the discharge advice note.

If the person is changing GP (discharging to a relative's address or new care home out of area), verbal communication is essential as paperwork or electronic documents may initially go to the usual GP practice.

Electronic palliative care coordination system

Electronic palliative care coordination systems enable the recording and sharing of people's care preferences and key details about their care with those looking after them. The systems enable communication between organizations to ensure that everyone involved in a person's end-of-life care is able to access key information to aid decision making. Such information can be viewed through IT systems used in primary care such as EMIS and SystmOne, and in some cases links in with secondary care systems. It is a government priority that, by 2018, these should be available in all localities to improve joined-up care, and that systems should be integrated across care boundaries.

Communication with out-of-hours services

Currently, many out-of-hours providers are not able to access the usual primary or secondary care clinical records. As many crises at the end of life will occur out of standard surgery hours, a proactive approach to sharing information with out-of-hours services should be undertaken, thus helping to prevent unnecessary readmissions when patients are unfamiliar to out-of-hours clinicians.

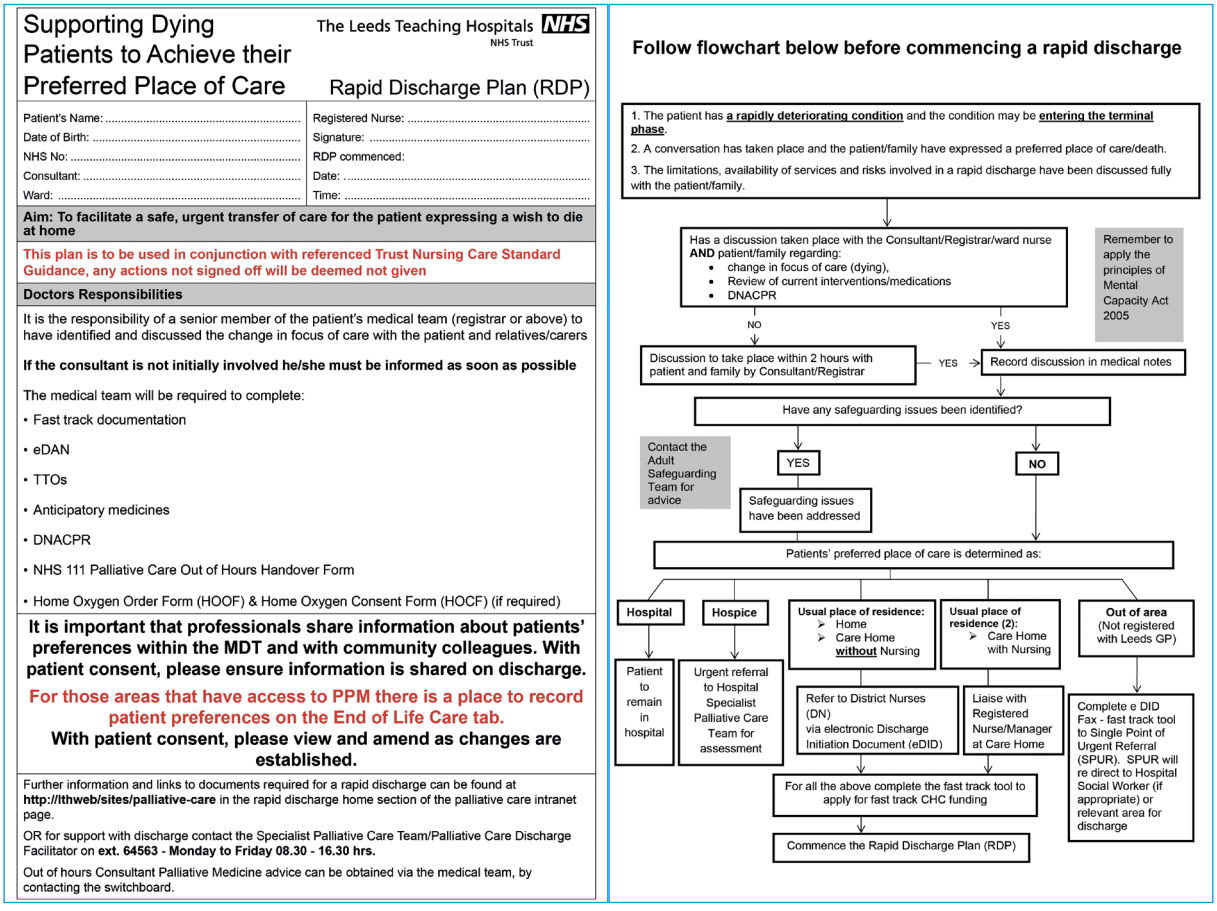
An example is the NHS 111 palliative care handover form which can be completed and faxed to the local out-of-hours service. Patients can then be flagged on their system as being 'palliative', enabling call handlers to respond more rapidly and appropriately if and when a crisis call is made.

Patient handheld records or care plans

Do not attempt cardiopulmonary resuscitation form: All patients who wish to die at home should have a do not attempt cardiopulmonary resuscitation form completed. The decision, and the presence of the form, should be discussed with all patients and their carers (unless there is a specific reason not to do so) in order that everyone is clear about what action to take in the event of the heart or breathing stopping, and the information can be quickly made available to any relevant professionals in the event of an emergency call out. Agreeing broader goals of care with patients and those close to them is an essential prerequisite to enabling each of them to understand decisions about cardiopulmonary resuscitation in context (*Figure 4*).

Care plans: Relevant nursing care plans or rapid discharge plan should be completed, copied and sent with the patient. These will provide essential information to the district nurse or carers in the community. Sharing essential information electronically should be the ultimate aim.

Figure 5. Example of rapid discharge plan resources.



Supporting Dying Patients to Achieve their Preferred Place of Care

The Leeds Teaching Hospitals NHS Trust

Rapid Discharge Plan (RDP)

Patient's Name: ..... Registered Nurse: .....
Date of Birth: ..... Signature: .....
NHS No: ..... RDP commenced:
Consultant: ..... Date: .....
Ward: ..... Time: .....

Aim: To facilitate a safe, urgent transfer of care for the patient expressing a wish to die at home

This plan is to be used in conjunction with referenced Trust Nursing Care Standard Guidance, any actions not signed off will be deemed not given

Doctors Responsibilities

It is the responsibility of a senior member of the patient's medical team (registrar or above) to have identified and discussed the change in focus of care with the patient and relatives/carers

If the consultant is not initially involved he/she must be informed as soon as possible

The medical team will be required to complete:

- Fast track documentation
- eDAN
- TTOs
- Anticipatory medicines
- DNACPR
- NHS 111 Palliative Care Out of Hours Handover Form
- Home Oxygen Order Form (HOOF) & Home Oxygen Consent Form (HOCF) (if required)

It is important that professionals share information about patients' preferences within the MDT and with community colleagues. With patient consent, please ensure information is shared on discharge.

For those areas that have access to PPM there is a place to record patient preferences on the End of Life Care tab.
With patient consent, please view and amend as changes are established.

Further information and links to documents required for a rapid discharge can be found at **http://ithweb/sites/palliative-care** in the rapid discharge home section of the palliative care intranet page.

OR for support with discharge contact the Specialist Palliative Care Team/Palliative Care Discharge Facilitator on **ext. 64563 - Monday to Friday 08.30 - 16.30 hrs.**

Out of hours Consultant Palliative Medicine advice can be obtained via the medical team, by contacting the switchboard.

Follow flowchart below before commencing a rapid discharge

1. The patient has **a rapidly deteriorating condition** and the condition may be **entering the terminal phase**.
2. A conversation has taken place and the patient/family have expressed a preferred place of care/death.
3. The limitations, availability of services and risks involved in a rapid discharge have been discussed fully with the patient/family.

Has a discussion taken place with the Consultant/Registrar/ward nurse **AND** patient/family regarding:
- change in focus of care (dying),
- Review of current interventions/medications
- DNACPR

Remember to apply the principles of Mental Capacity Act 2005

NO / YES

Discussion to take place within 2 hours with patient and family by Consultant/Registrar — YES → Record discussion in medical notes

Have any safeguarding issues been identified?

Contact the Adult Safeguarding Team for advice

YES → Safeguarding issues have been addressed

NO

Patients' preferred place of care is determined as:

Hospital → Patient to remain in hospital

Hospice → Urgent referral to Hospital Specialist Palliative Care Team for assessment

Usual place of residence:
- Home
- Care Home **without** Nursing

→ Refer to District Nurses (DN) via electronic Discharge Initiation Document (eDID)

Usual place of residence (2):
- Care Home with Nursing

→ Liaise with Registered Nurse/Manager at Care Home

Out of area (Not registered with Leeds GP) → Complete e DID Fax - fast track tool to Single Point of Urgent Referral (SPUR). SPUR will re direct to Hospital Social Worker (if appropriate) or relevant area for discharge

For all the above complete the fast track tool to apply for fast track CHC funding

Commence the Rapid Discharge Plan (RDP)

Special situations

Arranging end of life care at home for a patient in the emergency department or outpatients

The underlying principles for rapid discharge at the end of life remain the same in the emergency department or outpatients as those on a general ward. The process will differ slightly because of the different ways of working, e.g. time constraints, emergency care standard, 4-hour target.

In these situations verbal communication with professionals in the community is crucial to determine the person's or family's immediate needs and potential options for transfer. A person may already be known to the community team and have fast track funding, anticipatory medication and equipment already in place at home.

There may be other obstacles to a rapid discharge from the emergency department, such as availability of medication out of hours, and surmounting these requires identifying an end of life champion in the department, and close collaborative working to find solutions.

Alongside tailored education and dedicated clinical support the rapid discharge plan (*Figure 5*) can easily be adapted to support a specific clinical area.

Facilitating a patient to go abroad for end of life care

In some situations, patients will want to travel to their original country of origin, or to be with family or loved ones at the time of their death. Clearly, this is not usually possible in the last days of life, but if deterioration is recognized sufficiently in advance, transfer in the preceding weeks may be facilitated. Factors to consider include:

- Assessment of fitness to travel, including fitness to fly if appropriate
- Rules and assistance supplied by the airline
- Rules regarding transport of opioid and other controlled medication in and out of certain countries
- Provision of relevant medical details to allow smooth transfer of care to the new medical team abroad.

Transfer home in the context of addiction

A risk assessment needs to be undertaken when there is a history of substance misuse of the patient or someone living with them, particularly as many patients at the end of life will be discharged with drugs such as opioids and benzodiazepines (among others) which can be drugs of misuse. It may be that no change to plans is needed, or that medication is supplied in smaller quantities than for a standard discharge. Often such patients and their families are well known to GP services or specialist addiction services and it is important to agree a safe discharge plan that mitigates risk, but does not leave the patient at risk of untreated symptoms.

Homeless people

There may be some homeless people who choose to return to a hostel for end of life care. Careful consideration needs

KEY POINTS

- Early identification of the possibility that the person may be dying allows exploration of his/her wishes and priorities to help guide decisions around care.
- A joint approach to discharge planning at the end of life can be enabled by sensitive and timely communication with the person and those close to him/her.
- Rigorous care planning, using a systematic approach, led by an identified key worker is most likely to lead to a prompt and safe discharge.
- A person's preferences, needs and home situations are so diverse that individualised care planning is crucial.
- Effective liaison with, and communication of the person's needs and wishes to appropriate community services can avoid inappropriate readmission to hospital at the end of life, and help people to achieve their preferred place of death.

Figure 6. Aiming for excellence in palliative care discharge: improving on the standard model.

In striving to achieve successful, joined-up discharge planning at the end of life, the authors have found the following approaches and resources useful:

A strategic approach to discharge planning and organizational innovation

A city-wide strategic lead palliative care discharge facilitator is able to work across organizations at a senior level to lead on improvement systems within the hospital, provide expert leadership and knowledge for complex discharges, work with senior staff to identify issues and incidents and influence service change, and embed training and education around palliative care discharge into the organization

Within the authors' hospital, a multiprofessional discharge team with senior accountability (including representation from community, clinical education, nursing, occupational therapy and physiotherapy) supports complex discharges at ward level, including end of life care

A dedicated palliative care ambulance provides a bespoke, flexible and responsive service for patients at the end of life allowing them to be cared for in the place of their choice

A city-wide or regional approach

Operational differences between organizations can result in barriers to smooth discharge, and working to achieve consensus on issues such as first-line drug choices, opioid conversions and anticipatory prescribing can ensure a more seamless transfer of care and minimize the risk of errors. Recognizing the importance of this collaborative working, a managed clinical network has recently been formed locally to address these and other issues that impact on patient care, with support from the local clinical commissioning groups. Wherever possible, clinical guidance, education and research will be planned and delivered at a city-wide level

Specific resources

Within large organizations, and despite a rigorous education and training programme, there will always be the need for easily accessible clear guidance to support complex processes such as discharge at the end of life

As well as a wealth of information available on the trust intranet site, the authors' local rapid discharge plan (*Figure 5*) provides guidance to medical and nursing staff for a structured and coordinated process around end of life care discharge. Similar plans are in use in other UK trusts. Key to the success of the rapid discharge plan has been a systematic approach to roll-out and staff education

to be given to the potential risks involved in such a discharge including the limitations and availability of services in the community. An environmental risk assessment would need to be undertaken before discharge. Safety is paramount for both patient and community staff providing care. Patients can and have been successfully discharged to a hostel at the end of life. However, the majority of homeless patients tend to choose to die in a more safe and secure environment such as a hospital or hospice.

Conclusions

With appropriate assessment and a framework to work from, all hospital doctors should be aware of the key steps to discharging people home at the end of life, and feel confident in doing so. Recognizing when a person is nearing the end of life is fundamental to facilitating his/her wishes, and the person and his/her individual needs should be kept at the centre of the discharge process. A multiprofessional coordinated approach, with good communication between organizations, is crucial to achieving the best possible outcome for the person. The authors' approach to support excellence in palliative care discharge is outlined in *Figure 6*. **BJHM**

Conflict of interest: none.

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